EPA Hearing on Transparency in Data July 17, 2018
Testimony of Anne Mellinger-Birdsong, MD, MPH, FAAP

Hello. Thank you for allowing me to speak today. My name is Anne Mellinger-Birdsong. I am a Fellow of the American Academy of Pediatrics and a specialist in environmental public health. I have worked at city, county, state, and federal public health agencies and at Indian Health Service facilities.

I am here to speak in opposition to this proposed rule and to state that this proposed rule is unnecessary and would harm EPA's ability to evaluate health impacts of environmental pollutants. It should not be finalized or implemented.

This proposal has wording that makes it appear noble and well meaning. But it is a wolf in sheep's clothing. This proposal will severely hamper EPA's ability to use past and future research on health effects of human exposure to environmental chemicals and toxicants.

Both the Health Insurance Portability and Accountability Act (HIPAA)(1) and 45 CFR 46 Federal Regulations on Protection of Human Subjects(2) address privacy as a concern of people who participate in research.

It is not as simple as redacting data personally identifiable information redacted, as EPA officials stated when announcing this proposed rule. If the database is open to the public, it not only has to have personal identifiers redacted, it also has to not include information that can be used to figure out who a person is that participates in a study. For example, studies that examine air pollution contain research on heart attacks. If the data contains information about person X, age Y, in town A, who had a heart attack in July 2015, that might be sufficient information to identify who person X was. So even though the data does not contain name, birthdate, medical record number or other personal identifiers, people could still use the data to figure out who person X is. Therefore HIPAA and Human Subjects rules would prevent this data from being publicly available, and this rule would prohibit this study from being used.

All environmental studies require information on exposure to the substance or chemical being studied. Many studies do this by using residence zip code or census tract. Studies also use information on travel or commuting routes, school, or work locations. So again, residence data combined with age group data and disease information (asthma attack, hospital admission, etc.) could be used to identify people in studies. Some studies look at death due to exposures, others look at illness, symptoms, or hospital admissions of living people. Living people require more protections of their identity than studies of deceased people. Studies of children have even more human subjects protections.

People who participate in studies have concerns about the trustworthiness of the researchers and institutions, as noted by Carter et al in British Medical Journal (3). They also have concerns that private companies will not use their health data for marketing or other purposes that might be considered exploitive.

And as noted by Damschroder et al in Social Science & Medicine (4), people's trust in the researchers was the most powerful determinant of the kind of control they want over their medical records.

This proposed rule would eliminate consideration of many major studies on the health impacts of environmental pollutants. An example of one would be the 6 Cities study of air pollution and mortality published in 1993 (5). Probably the Children's Health Study conducted in southern California (6) would also be eliminated.

It would also likely decrease people's willingness to participate in future studies of environmental exposures, due to concerns about trust and privacy.

This rule is unnecessary. There are already HIPAA compliant and IRB approved methods to transfer data between researchers so that studies can be evaluated and verified, and to determine if findings can be replicated.

This rule would severely hamper EPA's ability to use already published scientific studies. It would also severely hamper future research on health effects of environmental exposures.

So I ask: why was a rule was proposed that would eliminate use of scientific studies and hamper future research, when the rule is completely unnecessary. This rule should not be finalized or implanted.

I will end with a quote by Carnegie Mellon University engineering professor M. Granger Morgan, who chaired EPA's Science Advisory Board under Republican President George W. Bush. He said the policy 'is an attempt by people who aren't interested in using science to find the truth "to raise doubts about what at this stage is very clearly established and well-reviewed science."'(7)

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